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Learning *about* Type 1 Diabetes and Learning *to Live with* Type 1 Diabetes when Diagnosed in Adulthood: Two Distinct but Interrelated Psychological Processes of Adaptation

A Qualitative Longitudinal Study

Mette Due-Christensen[1,2]; Ingrid Willaing[2]; Khalida Ismail[3]; Angus Forbes[1]

[1]Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, UK

[2]Steno Diabetes Center Copenhagen, Gentofte, Denmark

[3] Department of Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience at King's College London, London, UK

Corresponding author:

Mette Due-Christensen

mette.due_christensen@kcl.ac.uk

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Novelty statement

- We currently know little about the early experiences of adults **newly** diagnosed with Type 1 diabetes or how they adapt to a life with diabetes.
- This study shows that following the diagnosis of diabetes adults experience significant emotional distress and can quickly develop ongoing psychosocial problems that impact on their self-management behaviours.
- Following diagnosis adults need much more support in adapting to the condition emotionally, psychologically and socially. Such support may reduce or prevent the development of negative psychosocial reactions that can impede self-management behaviours and reduce well-being.

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Abstract

Aims

While half of all **people with** Type 1 diabetes **are diagnosed** in adulthood, little consideration has been given to the experiences of new-onset Type 1 diabetes in adult life. In this study we explored the experiences of newly diagnosed adults to understand the adaptive processes that occur in this early **phase** of the **condition**.

Methods

We conducted longitudinal semi-structured interviews with 30 adults newly diagnosed with Type 1 diabetes (age range 20-67 years; 16 men; median diabetes duration 23.5 months) recruited from hospitals in Denmark and the UK. The data were analysed using a narrative approach.

Results

The narratives were expressed in three thematic areas: the diagnosis; learning about diabetes; and learning to live with diabetes. Diabetes was characterised as a major disruptor to the established and future life plans of participants, causing significant emotional distress. The narratives showed: how early experiences triggered the development of ongoing psychological problems (fear of complications or hypoglycaemia) and diabetes distress; and that navigating different social scenarios (relationships and employment) can be challenging, leading to **suboptimal** self-management behaviours. The narratives also revealed that health professionals often did not attend effectively to participants' emotional needs following diagnosis and the language used frequently triggered negative feelings such as fear or a sense of failure.

Conclusions

Many of the common psychosocial problems associated with Type 1 diabetes seem to gestate in **the early phase of life with the condition.** There seem to be opportunities to enhance the support provided in this phase to minimise these problems.

Key words:

Type 1 diabetes; Adult; Psychosocial Factors; Self Care; Psychological Adaptation; Qualitative Research

Introduction

Over 50% of new-onset Type 1 diabetes presents in adulthood (1). While the psychological and social sequelae of being given a diagnosis of Type 1 diabetes are well described in childhood and adolescence (2,3), little is known about the psychosocial impact of diabetes in the adult onset population (4,5). The context of a diagnosis in adulthood is distinct, as people have consolidated their identities in areas such as employment and personal relationships. Hence, their emotional and behavioral responses to the diagnosis are likely to be different from those observed in children or adolescents. Adapting to diabetes in the adult onset population is also distinct, as people are usually given full responsibility for their self-management practices from the outset, without the same degree of external mediation and support as that of a child (6,7). Understanding how adults adapt to life with diabetes from diagnosis may help identify potentially modifiable processes which drive commonly observed psychological problems, such as: diabetes distress (8); depression and anxiety (9,10); and difficulties in optimising self-management (11), all of which are associated with sub-optimal **blood glucose levels** and increased risk of complications (12).

In this study we explored the adaptation processes that adults experience following their diagnosis of Type 1 diabetes in the hope of eliciting areas for supportive intervention to enhance the psychosocial well-being of adults during **this phase of life with Type 1 diabetes**.

Participants and Methods

To explore the experiences and adaptive **processes** that follow a Type 1 diagnosis in adulthood **we undertook a longitudinal qualitative study** address**ing** the following questions:

1. What are the experiences of adults following diagnosis?
2. How do adults adapt to life with diabetes physically, psychologically and socially**?**

The study followed a narrative approach (13). **The first author (MD) conducted face-to-face** in-depth interviews with people recently diagnosed with Type 1 diabetes. Follow-up interviews were conducted **over the telephone** six months from the first interviews, to provide a temporal perspective on their experiences and adaptation to life with diabetes.

Setting

The study was undertaken in Denmark and in the United Kingdom. Participants were recruited via large specialist diabetes centres in London (n=2) and in Copenhagen (n=3) serving socio-economically diverse populations. Collectively these centres treat around 120 cases of incident adult onset Type 1 diabetes per year. Depending on the context of their diagnosis, most adults with new onset Type 1 diabetes in these centres are generally given rapid education on blood-glucose **monitoring** and insulin administration at point of diagnosis, with outpatient follow-up by a multidisciplinary team of specialist **health professionals**.

Participants

Participants were recruited if they had received a medically confirmed diagnosis of Type 1 diabetes within the last three years and were aged >20 years. We identified potential participants through electronic registers and invited them by letter. **Guided by sample sizes in previous narrative research (13) we identified a** target sample of 30 participants divided between the two national contexts as **appropriate** to generate a robust theoretical interpretation of the adaptive processes. **Participants were purposefully sampled to ensure diversity of gender, age and time since diagnosis** to reflect different perspectives on the experience of the diagnosis **and the early adaptive processes** (13). **Following each interview MD appraised** the **information power** within the data **based on the quality of the dialogue. AF and IW subsequently appraised the collective data** to ensure a sufficiently broad scope of experiences to form narrative constructs to fulfil the requirements of the proposed analysis (14).

Data collection

We developed an interview guide**, the content of which** was **informed by** a meta-synthesis of previous qualitative studies (4). **People with diabetes and health professionals reviewed the guide to enhance the question style and content**. The guide was then piloted in both countries prior to data collection. The guide contained open-ended questions reflecting the research aims, and additional probing was used to fully elicit the narratives (see figure 1) (13,15). **The interviews were conducted in Danish and English, respectively, according to country of residence.** All interviews were digitally recorded and transcribed verbatim for analysis.

(figure 1 about here)

Data analysis

The analysis followed the principles of the narrative thematic approach outlined by Riesmann (13). The narrative approach explores the participant's experience as a story, focusing on three essential elements: text (how and where the story is told and the characters within the story); time (sequencing events and change); and meaning (interpreting the story and how it is expressed). The initial and follow-up interviews were analysed together to provide an integrated longitudinal perspective on the narratives (15). The analysis was conducted in the following steps:

1. Familiarisation with transcripts (reading and rereading).
2. Identification of characters and settings relevant to the participants` experiences before, during and after diagnosis.
3. **Identification of adaptive processes that unfolded over time since diagnosis and potential changes in these between the first and second interview.**
4. Thematic analysis involving coding of themes that emerged in the narratives. The data were coded in segments, rather than word by word, to keep the narratives intact. The preliminary

coding framework was organised into two dimensions: one relating to experiences of the diagnosis; and the other to phenomena that participants described as influencing their adaptation to life with diabetes.

5. The preliminary dimensions were subsequently expanded inductively into themes and sub-themes to provide a more detailed interpretation of the narratives **including potential change over time.**
6. The similarities and differences within and between the accounts were identified to explore patterns within the data reflecting diversity of perspectives.

The **first author analysed the data**, with two other researchers cross-checking the codes and themes (disagreements were resolved through discussion). NVivo 10 was used to organise the data (16).

The study received ethical approval from the National Health Service ethics committee in the UK (15/NW/052) and from the Data Protection Agency in Denmark (SDC-2015-023-Kings-I-suite-03470). To protect the anonymity of the participants, pseudonyms and a **10-year** age span rather than their actual age **follow each quote**. **The number of months since diagnosis at the first interview is also reported.**

Results

In total 62 adults with new onset Type 1 diabetes were invited to participate in the study. Of the 33 potential participants who responded three declined **due to time constraints**. Recruitment ceased once 30 participants were identified, all of whom took part in the initial interview. Twenty-eight participated in the second interview; one participant **did not respond, and another declined due to personal reasons.** The median age of participants was 29 years (range 20-67 years). The sample was evenly divided by gender and distributed across the age range, with a slight preponderance toward younger adults. **According to information retrieved from their medical records a** third had sub-optimal **blood glucose levels** (see Table 1).

(Table 1 about here)

The experiences of the diagnosis and the following process of adaptation were remarkably similar across the two countries. Therefore, the results of the narrative analyses are presented in one analysis, beginning with an overview of the narrative structure followed by the primary themes identified within the narratives considering: the experience of diagnosis; **followed by the processes of** learning about diabetes; and learning to live with diabetes. **Quotes supporting the findings are placed directly in the text or are referenced in Table 2, 3 or 4. Quotes are explicitly contextualised or referenced in the descriptions of each theme.**

Narrative structure (overview)

The narratives were played out in three main scenes: life pre-diagnosis; the health care system; and everyday life (home, work, and social settings). The narratives relayed how the appearance of diabetes

into these scenes altered the way participants conducted their routines and interactions with others: "*I don't want to be about to hypo* [at work], *that's the most scariest thing especially in front of other people, so you check again, if your eyes go fuzzy you think, am I too low or high? And it's like that all day!"*(Kath, thirties, 24 months). The narratives' main physical characters were: themselves; their friends, family and acquaintances; and **specialist** health professionals, who were novel to their life context: "*The health professionals do their best and want the best for you, but it's still kind of weird that others are in control of your life" (*Mary, twenties, 19 months). Diabetes was identified as a metaphorical character; a new entity cohabiting within their lives and was generally referenced in the third person: *"it's exhausting…like carrying a baby around with you, you always have to take care of it, you can't leave it…and walk out, you can't take your eyes off it"* (Ian, twenties, 15 months). The narratives often began with accounts of the physical symptoms around the diagnosis and then of the disruption diabetes brought to their lives physically, emotionally and socially: *"It has been a huge change. The freedom I used to have is now very restricted…I have to plan everything"* (Alice, sixties, 33 months). The narratives then spoke in parallel about participants' need to learn about the **condition** and acquire self-management skills; and how they needed to learn to live with **diabetes**, reflecting on the impact of diabetes in the context of their past, present and future lives. **Although the narrative structure was common, the temporal sequence of the stories was not straightforward, as the narratives were to some extent circuitous, continuous and open-ended. The ongoing process of adaptation was reflected in the fact that although participants had become more familiar with self-management practices at the time of the second interview, they continued to encounter situations they had not experienced before necessitating further adaptive responses.**

*The **experience of** diagnosis*

The narratives suggested that the experience of a diabetes diagnosis is distinct to each individual. However, the data also indicated that some common events seem to shape the way in which people respond to their diagnosis and move on to accommodate diabetes in their lives. Two sub-themes emerged within this aspect of the narrative and these are described below with supporting data in Table 2.

(table 2 about here)

The time of diagnosis

From the first presentation of physical symptoms, the time around diagnosis constituted a period of uncertainty and participants often endured prolonged symptoms before seeking help. The delay **some participants experienced regarding** the diagnosis was in part related to the failure to associate Type 1 diabetes as a **condition** that occurs in adulthood. **Indeed**, some participants were misdiagnosed with Type 2 diabetes which they found frustrating: *"I felt really bad after starting on Metformin and I lost weight"* (Alice, sixties, 33 months). Once the diagnosis was conferred, many participants initially felt

relieved, as they now knew what was wrong with them and their physical symptoms dissipated with the introduction of insulin. For most participants this relief was short lived, however, as they began to realise the potential seriousness of their condition and its impact on their lives.

Introduction to diabetes

The initial communications received from health professionals were very important in shaping participants' perceptions of diabetes. **While some health professionals initially painted a threatening picture of life with diabetes emphasising the hazards of not attending to it, more** commonly health professionals sought to assuage the participants' anxiety by downplaying the seriousness and complexity of diabetes by saying it '*wasn't that bad*' and that diabetes '*just had to be managed*'. However, this type of reassurance also had a negative impact. This underplaying of diabetes meant that some participants did not initially **understand** the importance of self-management behaviours, and later became frustrated when they realised that diabetes did need special attention.

Learning about diabetes

Following the diagnosis participants had to learn about diabetes, its treatment and the technical skills they needed to self-manage their condition. The narratives revealed that this was largely self-directed experiential learning as the different facets of life with diabetes presented themselves **over time**. Several sub-themes emerged within this aspect of the narrative and these are described below with supporting data in Table **3**.

(Table **3** about here)

Learning self-management

The narratives revealed that participants rapidly had to learn self-management behaviours which was initially overwhelming: *"I couldn't take it in at all"* (Mary, twenties, 19 months). Once the participants acquired the basic skills they began to realise that it was very demanding to sustain these behaviours in their day-to-day lives. **While performing self-management behaviours became routine after some time, participants found they had to constantly be alert.** Participants also learned that self-management was not straightforward as they discovered that there was a high level of complexity in considering how their blood glucose might respond to different foods or activities. This complexity was associated with a sense of frustration as participants found it hard to maintain a specific glucose level **over time.** The idea they had been given that they could continue as normal and eat or do what they wanted seemed misleading. Some participants were concerned that they lacked the numeracy skills to manage their diabetes, engendering a sense of inadequacy and failure

Encountering hypoglycaemia

Learning about diabetes also included learning about the effects of insulin and in particular the

experience of hypoglycaemia. Participants began to associate factors that could trigger hypoglycaemic episodes such as exercise or over-estimating the energy content of a meal. They quickly learned that hypoglycaemia was extremely unpleasant and adopted compensating behaviours to avoid it. Conversely a few participants became more concerned about developing complications and were more inclined to run their glucose level low, even if it resulted in hypoglycaemia and loss of awareness: *"I cannot detect when my blood sugars are low. I have a Glucose Sensor that alerts me when the blood sugar is low"* (Mark, thirties, 28 months). The narratives also revealed how these experiences impacted on relationships potentially triggering stress and anxiety in partners.

Hyperglycaemia

In terms of learning about hyperglycaemia, participants' focus shifted from the acute symptoms they had experienced at diagnosis to the realisation that Type 1 diabetes can cause significant complications **in the future**. This engendered a fear response in some **which was maintained over time**. Hyperglycaemia was also perceived as failure, as participants felt unable always to achieve the blood glucose targets that were externally prescribed by health professionals leading to feelings of anxiety, frustration and even to embarrassment. **These feelings could potentially result in concealment of the condition.**

Learning to live with diabetes

Following diagnosis, participants were faced with the fact that their lives had radically changed, and they **began** to process what this meant for them now and in the future. The narratives relayed the psychological and social adaptation to diabetes. **These were processes that unfolded over a long period of time and seemed to be ongoing**. The narratives suggested that participants found learning to live with diabetes much harder than learning about diabetes: *"It's quite easy to learn…how it works with insulin and everything but what's hard is the mental [part] to learn to live with it in your brain and with yourself and accept it…this is the most important part"* (Tony, twenties, 5 months). The sub-themes within the narratives around learning to live with diabetes are presented with supporting data in Table **4** and are summarised below.

(Table **4** about here)

Disruption

Learning to live with diabetes was driven by participants' perception of the disruption diabetes brought to their' lives **as they gradually became familiar with the condition**. For all participants the immediate impact was identified as being much more significant than anything else they had experienced, as most of their previous illness experiences had been transient and did not involve a permanent and major reconstruction of their life. The disruption had different emphases **as their lives with diabetes unfolded;** in part it was about losing the capacity for spontaneity and flexibility; but it was also related

to the need to be constantly cognisant of diabetes to an often-overwhelming degree. Another aspect of disruption was the impact diabetes had on life schedules, such as having to plan home and work routines to accommodate the self-management demands of diabetes. The disruption infiltrated their future lives altering career plans, plans for relationships and the prospect of a family.

While this sense of life disruption was common to all participants, it was nuanced differently in the younger and older participants. Those in their twenties contextualised their diagnosis alongside other transitions they experienced: *"the diagnosis was a lot more overwhelming than anything else I'd felt…like, you know, university"* (Nick, twenties, 17 months). For older participants the diagnosis was expressed as an unanticipated intrusion into their established lives: *"it was the biggest punch in the gut that I've experienced so far. I was more than 60 years old when I got it…it completely knocked me off my feet"* (Kevin, sixties, 23 months). **The younger participants reflected a little more positively to their diagnosis. A common statement was that they now appreciated life more and had become more aware of their health and values. On the contrary, the older participants had already formed their identity and settled with ways of conducting their lives that gave them a sense of meaning. The diabetes diagnosis challenged their sense of identity and direction, causing them to uproot their set ways and make adaptations that they felt negatively affected their quality of life.**

Emotional response

The diagnosis and ensuing life disruption triggered a significant and enduring emotional response. The narratives relayed a grief for participants' lost life, with a mixture of emotions including **sadness** and uncertainty about the future and fear of the unknown. The loss identified by participants was multifaceted reflecting physical loss– a loss of a normal body; loss in the context of the freedom to make everyday choices without any immediate consequence. The experienced emotional distress was often expressed in existential questions, such as '*why me'* or '*what did I do to deserve this"?* During this period participants often felt alone with their emotions and questions, and they felt that health professionals did not seem interested in how they were coping mentally with their diabetes. Participants saw health professionals as being more focussed on glucose levels than their psychological and social well-being.

Acceptance

A key feature of the adaptive processes in the narratives was the extent to which the participants began to accept their condition. It was clear from both the initial and second interviews that accepting diabetes had multiple components and was a challenging and lengthy process **as they encountered new situations.** None of the participants had accepted their diabetes in its entirety at the second interview. While they had accepted that they had diabetes, they struggled to accept the demands **and limitations** the **condition** placed on them. The level of acceptance seemed **somewhat** relative **to duration of diabetes, however, this was not always the case as some with longer duration continued to struggle with aspects of acceptance.** A few participants identified that acceptance was related to

their perceived success in managing their diabetes: the less successful they felt they were**,** the less accepting they became.

Social adaptation

The entrance of diabetes into the participants' social habitus, demanded adaptations in their relationships, social interactions and working lives. In terms of intimate relationships, diabetes could make interactions more complex. A common area of difficulty was when the partner wanted to participate in the person's self-management. This could either be perceived as supportive or as a source of conflict. In terms of the more generalised social context, there were issues within the narratives that related to personal confidence in revealing diabetes and asserting needs in unfamiliar situations. That level of confidence was also influenced by stigmatising factors such as being judged negatively by others in relation to diabetes or behaviours (such as injecting or eating). For many participants diabetes had a major effect on their working lives, with anxiety about work performance being a major concern, particularly in the context of hypoglycaemia. This anxiety was associated with **suboptimal self-management** such as running glucose levels **too** high when undertaking **specific** work tasks. For some, work challenges were more practical such as having the time and/or a suitable place to **check blood glucose** or inject **insulin**; being released for doctor's appointments together with general work stress. As with emotional support, participants felt that the guidance and support provided by health professionals around employment was lacking**. These experiences were common to both genders and across the age groups independent of type of work.**

Discussion

This study has provided a unique insight into the early experiences of adults with newly diagnosed Type 1 diabetes. **The narratives in some way revealed the hidden story of the lengthy process of adapting to diabetes by relaying personal diabetes journeys. Journeys that most participants found to be unexpected, challenging and unwelcome. The narratives also showed that important psychological and social adaptive processes took place in this early phase of diabetes such as: their psychological orientation to diabetes (acceptance/rejection, anxiety/distress); their understanding of and confidence in self-management; and how they managed diabetes in social and work situations. The narratives suggested that while adaptation to the condition is an ongoing process,** it is also clear that many of the common psychological problems observed in diabetes gestate early **after diagnosis**, such as fear of hypoglycaemia and complications (17,18). Given the general orientation of diabetes care toward preventing complications it would seem useful to consider addressing these potential problems early after the diagnosis, as they can contribute to **sub-optimal** self-management increasing the risk of long-term complications (**5**,11-12). **The limited number of** psychological interventions **and resources deployed in diabetes, are currently** used to **support** people with established diabetes (**5**,19,20). **While people at all stages of diabetes may require emotional support or psychological intervention, providing more** psychological

intervention following diagnosis before **these problems** become habituated **may reduce the severity and extent of the psychological problems in the diabetes population. However, it is also important that people receive ongoing psychological support, as the data also showed that over the three-year window we have explored, new challenges continued to occur necessitating further adaptive responses. Attending to these psychological needs may also impact positively on clinical outcomes, as** the narratives show how psychological problems can lead to **suboptimal self-management**, such as **running blood glucose too high to avoid hypoglycaemia**. Social factors were also observed to interplay significantly with self-management, including areas that have previously been identified in people with longstanding diabetes, such as: work performance (21); managing relationships (22-23); social identity and self-image (24); and the experience of stigma or discrimination (25). Therefore, providing adults with strategies to navigate the social impact of diabetes following diagnosis may help improve their self-confidence in attending to diabetes in public contexts, thereby enhancing their self-management **and well-being**.

It was clear from the narratives that there was much emotional turmoil in this early period of life with diabetes, reflecting many of the components of the grief response, such as anger, **sadness** and denial (26). However, these feelings were not adequately addressed, leading to diabetes distress at an early stage. Given the high levels of diabetes distress that have been reported in the general adult diabetes population (8,27), it would seem pertinent to provide more psychological support just after a diagnosis in adulthood and allow some space and support for people to consider the existential questions that occupy their minds. Such support may increase acceptance of **diabetes**, which again may increase **well-being and** self-management activation, as low acceptance has been associated with reduced self-management engagement (28).

The study also revealed important factors in people's interactions with health professionals. There seemed to be a disconnection between the intention of the communication from professionals and peoples' experiences of that communication. Trying to palliate people with responses such as *"everything can be normal",* generally did not resonate well with what people experienced and felt. It is increasingly recognised that the language used in diabetes care may not always be helpful for people with diabetes (29). For example, assigning glucose targets and levels as good or bad may convey a sense of failure leading to reduced engagement in self-management and may drive fear of complications (30). Therefore, equipping health professionals with strategies to communicate the diagnosis and interact with people early after diagnosis in a way that is more reflective of peoples' experiences may improve **their perception of diabetes** and their engagement with the diabetes team.

The study's strengths were the inclusion of several clinical settings in two countries and a relatively large and diverse group of people in relation to age and duration of diabetes compared to previous studies of the population (4). While the findings are likely to be transferable to similar populations attending specialised clinics in westernised societies, caution must be taken in relation to populations in countries with different cultural contexts,

health care systems and health resources. Coding conducted by one researcher is a potential limitation of the study, however, the coding was developed iteratively with two other researchers and themes were agreed through group discussion and checked against original transcripts.

Overall, the central message of the study is that it is as important to focus on supporting adults from diagnosis to learn 'how to live with diabetes' as much as it is to learn 'about diabetes'. Attending to the emotional impact of **diabetes**; **supporting** adults to develop more positive adaptive **strategies**; and enhanc**ing** communication by health professionals following diagnosis, may help attenuate the development of common diabetes specific psychosocial problems. **Further research is needed to develop such tailored interventions in collaboration with people with diabetes and health professionals.**

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Table 1 Participant Characteristics

Characteristic:		***All (n=30)***	***UK (n=16)***	***DK (n=14)***
Gender				
(n=)	Men	16	8	8
	Women	14	8	6
Age				
(years)	mean	35.7	32.1	39.9
	median	29	27	37.5
	(range)	(20-67)	(21-67)	(20-64)
Duration diabetes				
(months)	mean	21.5	19.4	23.9
	median	23.5	16	26
	(range)	(3-46)	(4-46)	(3-38)
HbA1c at diagnosis				
(mmol/mol)	mean	108 (n=24)	103 (n=12)	114(n=12)
	median	111	101	112
	range	(60-171)	(60-137)	(66-171)
(%)	mean	12.1	11.5	12.6
	median	12.3	11.4	12.4
	(range)	(7.6-17.8)	(7.6-14.7)	(8.2-17.8)
HbA1c at 1st interview				
(mmol/mol)	mean	56	54	59
	median	48	48	52
	(range)	(37-138)	(37-84)	(40-138)
(%)	mean	7.3	7.0	7.6
	median	6.5	6.5	6.9
	(range)	(5.5-14.8)	(5.5-9.8)	(5.8-14.8)
HbA1c at 2nd interview				
(mmol/mol)	**mean**	**56 (n=26)**	**51 (n=12)**	**61 (n=14)**
	median	**52**	**46**	**62**
	(range)	**(37-85)**	**(37-84)**	**(40-85)**
(%)	**mean**	**7.3**	**6.8**	**7.7**
	median	**6.9**	**6.4**	**7.8**
	(range)	**(5.5-9.9)**	**(5.5-9.8)**	**(5.8-9.9)**

Table 2 The experience of diagnosis – narrative subthemes

Subthemes^	Supporting data	Participant*
THE TIME OF DIAGNOSIS		
Prolonged symptoms	*"I was probably more like the kind of person who would say, 'Well, I don't have to do anything, I'll be fine soon' I usually am"*	Harry, forties, 28 months
Relief	"*After a few days at the hospital I could feel all the energy return to my body and suddenly I could walk a flight of stairs…Some things were positive because my body was feeling so much better*"	Dan, twenties, 31 months
INTRODUCTION TO DIABETES		
Scare tactics	"[A]*consultant…told me and I'm not exaggerating, that I was going to have a heart attack when I was 50, I'd never be able to drive again, and I'd never…eat any chocolate or anything like that…again. And I was pretty shocked, because I didn't know anything about diabetes and I'd just been diagnosed*"	John, thirties, 31 months
Down-playing	*"They* [the health professionals] *have been very sweet and hugely supportive…actually a little too much. You know, it is as if they unintentionally made it less bad than it should be; 'You can easily have a slice of cake you only need to take some extra insulin…this disease can easily be managed'…And that's why I wasn't as strict with my blood sugars"*	Bea, thirties, 16 months

^Subthemes in capital letters and underlined with descriptive words linking the quotes to the result section. *Name (pseudonym), 10-year age span, the number of months since diagnosis at the first interview

Table **3** Learning about diabetes - narrative subthemes

Subthemes^	Supporting data	Participants
LEARNING SELF-MANAGEMENT:		
Pressurised learning	*"It's not the kind of thing you ease yourself into. I mean, you have to start doing it right away"*	John, twenties, 31 months
Demanding	*"You know it's really tedious. Measuring blood sugar and taking insulin four times every day. I think it's such a bother having to do that"*	Mary twenties, 19 months
Ongoing	*"Of course, the longer you've had diabetes it [self-management] becomes more and more of a routine. But I still have to do it… it takes up a lot of time and requires good planning"*	Curt, forties, 38 months
Complexity	*"I mean testing your blood takes about ten seconds; injecting yourself…20 seconds…It's the associated things that take a lot more time and the internal dialogue 'Oh can I do this, can I do that?'"*	Bob, twenties, 13 months
Frustration	*"What they say is, 'Just eat normally. You'll be fine. You can do this.' No, you can't! It's a load of crap"*	Jack, thirties, 4 months
Numeracy	*"If this is a numbers game, that's what this disease is about, I'm probably not as confident…as I thought I would be…the same feeling I used to get in Maths class at school"*	Sue, twenties, 4 months
ENCOUNTERING HYPOGLYCAEMIA		
Learning about hypoglycaemia	*"I did a lot of exercise…without having much food. And I woke up in the middle of the night, about 1am, tested my sugars, and I was 1.9"*	Bill, twenties, 36 months
Avoiding hypoglycaemia	*"I was terrified of hypos and I still am. And I kept my blood levels higher and higher and then I got into that bad routine…Now I think it's more a behavioural thing and I think it's, I'm just so scared"*	Amy, twenties, 38 months

Subthemes^	Supporting data	Participants
Running low to avoid complications	Mark explains why he runs his glucose level low:" *[There's the] fear of being so unwell that I can't do anything myself…I haven't passed out as such yet where I needed an injection but lots of times others have had to feed me and that's not a great feeling at all. It's rather humiliating"*	Mark, thirties, 28 months
Impact on relationships	*"I didn't want to scare Sara [Girlfriend]. But it got to the point where I was in such trouble that I had to crawl from the kitchen...to my bedroom and I had to wake Sara up by holding onto her foot and saying, 'Help'…a bit emotional…I said to her it would never happen again"*	Bill, twenties, 36 months
HYPERGLYCAEMIA		
Fear of complications	*"And then you think about... I don't know... what happens if I don't control everything well and I go blind? I feel like the future worries part is a lot worse for me than the actual… happening part"*	Helen twenties, 32 months
A sense of failure	*"Well, it turns out I cannot control it. Two and two actually doesn't add up to four… It doesn't work that way…It is extremely frustrating for me that I can't manage it properly"*	Alice, sixties, 33 months
Concealment and embarrassment	*"If…my blood glucose is too high I'll take some insulin before I measure it [giggles] because otherwise he [the doctor] can see on my meter that it's too high… and expose me if I have been naughty"*	Bea, thirties, 16 months

^Subthemes in capital letters and underlined with descriptive words linking the quotes to the result section. *Name (pseudonym), 10-year age span, the number of months since diagnosis at the first interview

Table **4** Learning to live with diabetes – narrative **sub**themes

Subthemes^	Supporting data	Participant*
DISRUPTION		
Capacity for flexibility	*"Normally I'd go bike ride, cycle for miles sort of non-stop. Whereas now I just need to take pit stops and just check where I'm at and I always feel like I'm kind of like encumbering people I'm with because I say no I'm sorry got to stop now, watch my blood sugars, maybe have something to eat"*	Nick, twenties, 17 months
Constant awareness	*"So now it's more this idea of having to think about diabetes all the time, after having lived 40 years without… this abrupt change from having a normal life…to having a life where you really have to be in control of yourself"*	Harry, forties, 28 months
Life schedule	*"So, it affects my work, I'm always checking my blood sugar at work, I'm always wondering in a meeting whether or not I'm high or low and I can't play a game of football, run for the bus, have sex, get drunk…without at least giving a little bit of preparation…a change for someone in their twenties"*	Ian, twenties, 15 months
Family life	*"Well, my day is organised so that I have time to take my insulin before having something to eat and then getting the kids ready. Not many things have to go wrong before things are a mess"*	Mark, thirties, 28 months
Future life plans	*"It's all the things I'm not able to become that are the most annoying part. That's what takes up a lot of thought. Although I've given that up* [becoming a police officer] *I'll probably always think about it. I'm finding it difficult to work out what to do now"*	Jonas, twenties, 24 months
Positive effect	*"I value myself more and I make more conscious decisions health wise"*	Sue, twenties, 4 months
Negative effect	*"The thing is it's… it's happened right at a point of my life where I've actually just got comfortable with myself and now I have to change everything again… I didn't have this all my life, I've had this literally in the middle of my life, there's no way I'm going to bloody change"*	Jack, thirties, 4 months

Subthemes^	Supporting data	Participant*
EMOTIONAL RESPONSE		
Loss of previous life	*"So, your whole life... they don't tell you that. Oh, by the way. The life you knew has gone out the fecking window. Say goodbye now cause it's gone"*	Jack, thirties, 4 months
Sadness	*"Actually, I was just sad... I cried... when I saw it* [the blood glucose reading] *...I cried, and I tried to call my girlfriend. I was miserable"*	Jeff, twenties, 3 months
Uncertainty about the future	*"The occasional niggly thought of if I don't manage it what could go wrong"*	Adam, twenties, 19 months
Physical loss	*"Suddenly I had this condition where I just, it was so personal, and I felt like I knew it wasn't my fault but then again it kind of was my body's fault and if your own body can randomly attack itself I didn't really feel safe in a way.*	Lisa, twenties, 35 months
Loss of freedom of choice	*"I felt trapped… I couldn't just do whatever I felt like doing"*	Polly, forties, 9 months
Existential reflections	*"I told myself 'Why me, why now?', because I was just about to graduate from my master's and start working and it was the worst timing ever. So I got really, really sad"*	Tony, twenties, 5 months
Lack of psychological support	*"They don't ask, whenever I see anyone here [at the diabetes clinic], they don't ask 'How are you dealing with it mentally?', nobody does"*	Kath, thirties, 24 months
Focus on numbers	*"Just because someone's doing well physically and managing the condition doesn't necessarily mean it's not having a psychological impact…I don't think anyone has ever said… 'How are you feeling'"*	Bob, twenties, 13 months
ACCEPTANCE		
Time	*"I think time is important [for acceptance]. It's not like a flick of a switch…there are days when something new happens…you're not ready for it…and I found that I just have to deal with every situation"*	Bill, twenties, 36 months

Subthemes^	Supporting data	Participant*
Demands	*"I've come to terms in the fact that I can't get rid of it. That's it. I've got it. I've nearly come to terms with things I have to do and things I mustn't do and things I can't do. So, I'm getting there, but… [it's] a very slow process"*	Judy, fifties, 5 months
Limitations	*"Well, I don't have a relationship to the disease as such. It's the limitations it imposes on me I can't accept (…) the fact that I can't perform to the degree I would like to"*	Alice, sixties, 33 months
Management	*"If you say…'Accept that you have to manage it'…that has more positive connotations…and for me that means testing frequently, eating the right foods…all that kind of stuff".*	John, thirties, 31 months
Denial	*"So I might still be in denial. I think I've accepted I'll have this for the rest of my life but it's accepting that I have to control it….so maybe I'm not at acceptance yet"*	Amy, twenties, 38 months
Resistance	*"I'm never going to accept diabetes. I'm going to be one of those people…. I will still eat bags of sweets because…I didn't grow up as a baby diabetic, I didn't have this all my life, I've had this literally in the middle of my life, there's no way I'm going to bloody change"*	Jack, thirties, 4 months
SOCIAL ADAPTATION		
Intimate relationships	*"It may be that those I'm dating think, 'Oh, she's one of those, she's difficult, she has a chronic condition. If we grow old together she may lose her feet or get something', you know? I think a lot about that"*	Bea, thirties, 16 months
Partner involvement	*"She* [girlfriend] *only wants the best for me and she can support me in the choices I make. When I'm in* [the shop] *and just want to buy some cake and put it in the basket, I don't appreciate her saying: 'I think that's a bad idea,' when I've had a bad day and just want something"*	Tom, twenties, 32 months
Disclosing diabetes	*"Yeah, I feel like definitely the hardest thing is telling, having to tell people and understanding that their opinion on your ability might change, even though it won't"*	Nick, twenties, 17 months
Asserting own needs	*"You know when someone else is going to cook for me…I now try and assert slightly more strongly what I need them to provide me with, rather than simply having what they've got"*	Linda, sixties, 34 months

Subthemes^	Supporting data	Participant*
Stigma	*"The things people say sometimes, if they see you injecting…once this girl at uni said, 'Oh, if I had to inject myself every day, I'd kill myself.' And I was like, 'Why do you think that's a good thing to say?*	Helen, twenties, 32 months
Work performance	*"If I'm at work and I need to give a presentation…I kind of feel like this conspires against me because, I have to worry about 'Am I nervous or am I having a hypoglycaemia?' You know all these ridiculous, little things, but they can affect you"*	Ian, twenties, 15 months
Running blood glucose levels high	*"If they said to me at work 'can you go and do a viewing?'…I'm going to eat a sweet to make sure I'm high enough, perhaps too high, to make sure I don't hypo"*	Kath, thirties, 24 months
Guidance about work	*I think there's…especially newly diagnosed as an adult*…[there's]*things like no-one really tells you…how it's going to affect you at work"*	Jane, twenties, 5 months

^Subthemes in capital letters and underlined with descriptive words linking the quotes to the result section. *Name (pseudonym), 10-year age span, the number of months since diagnosis at the first interview

Figure legend:

Figure 1 Interview Schedule